

Advance Directives to Manage Fears and Anxieties of Transgender People via Dementia Planning

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Abstract: As increasing proportions of our global population age, transgender people are experiencing higher rates of dementia, and many are afraid to enter long-term care. Structural interventions such as advance directives may help mitigate fears around entering long-term care by managing specific anxieties that transgender people may have about dementia, loss of decision-making capacity, and discrimination in long-term care settings.

Transgender health has been less researched compared to the health of the broader lesbian, gay, bisexual, transgender, and queer (LGBTQ) community or overall population health. There is a particular need for more studies of the experiences of older transgender people generally and of dementia in particular.¹ But as the proportion of older adults increases, more research is emerging. The purpose of this integrative synthesis is to bring together research on aging, dementia, mental health, discrimination, and advance care planning among transgender adults in order to propose a new tool to assist transgender people with planning for dementia.

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Methods

Because this literature review was based in law and policy and sought to bring together multiple disparate areas of study, a review protocol was not strictly followed.

Eligibility Criteria

This review looked for evidence related to (a) people who identify as transgender, nonbinary, or any other gender identity than cisgender (although not always overlapping, these identities are referred to throughout this article as “transgender”), (b) diagnosis and treatment of dementia in transgender people, (c) fears and anxieties that transgender people may have about loss of legal decision-making capacity, (d) vulnerability to discrimination in long-term care settings related to maintaining gender identity, and (e) advance care planning among transgender people.

Information Sources

A Web of Science search was conducted for dates 1/1/2018 – 1/4/2023. Additional articles that were published during drafting or found through citation searching were also included.

Results

The Web of Science search netted 2,640 results which were screened by title, 182 studies by title and abstract, and 24 articles by full text review. Analysis yielded themes related to the five topics above, which in turn shaped the sections of the discussion. Direct quotes from transgender people are used when relevant, but there remains a need for more stories shared by transgender people living with dementia.²

Discussion

A. The Background Context of Transgender People's Lives

The population of the United States is rapidly aging, with the population aged 65 and over projected to nearly double by 2060.³ Current estimates are that there are 171,700 transgender people aged 65+ in the US, with almost twice as many in the US South than any other part of the country,⁴ important because the South has so few legal protections for transgender people.⁵

Transgender people who might prefer aging in place may be faced instead with entering a residential long-term care facility.⁶ One reason is that it may be more

Higher levels of marginalization have been associated with negative reports of health among LGBTQ older adults.²⁰ Therefore, it is not surprising that chronic minority stress in LGBTQ elders heightens the risk for premature cognitive aging.²¹ Black and Latine LGBTQ older adults were significantly more likely to report cognitive difficulties.²²

B. Dementia Among Transgender People

The same association with brain health disparities is true for transgender people who experience heightened marginalization. Older transgender people may face more health disparities than cisgender people, including higher rates of depression, stress, disabil-

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difficult for them to find supportive family members to be caregivers.⁷ Among transgender adults age 65+, new survey data show that only 63% reported support from immediate family members.⁸ Higher proportions of transgender people who are Asian and Pacific Islander,⁹ Black,¹⁰ and Latine¹¹ (a gender-neutral term for people of Latin American ethnicity¹²) experienced family rejection, with the biggest disparity among transgender Indigenous people.¹³

Another reason is that transgender people are less likely to be able to afford in-home care. Affordability is an issue since transgender people are more likely to be low-income (34%).¹⁴ Transgender Black, Indigenous, and people of color (BIPOC) are disproportionately likely to be low-income, with the biggest disparity among transgender Latine people at 43%.¹⁵ Some state Medicaid programs do cover in-home care under Home- and Community-Based Services waivers, but almost always with a waiting list.¹⁶ Even if in-home care providers are affordable, they often have a learning curve with caring for transgender people.¹⁷

Almost 1 in 2 transgender people, including 68% of transgender people of color, reported experiencing mistreatment from a healthcare provider.¹⁸ Transgender people have reported being misgendered and subject to ridicule, receiving substandard or delayed care, and being denied care altogether by long-term care providers.¹⁹

ity, and poor health.²³ Transgender people are more likely to report poorer brain health as they age: nearly 16% of transgender and nonbinary participants rated their memory as poor/fair, and 17% reported that their memory was worse than the previous year.²⁴ A study of administrative data shows the prevalence of risk factors for Alzheimer's disease is 2–3 times higher for transgender adults,²⁵ and the same rates have been reported in England.²⁶ Rates were almost nine times higher in a study of over 1,200 transgender veterans.²⁷

Transgender people were 5.7 times as likely to report subjective cognitive changes with memory or logic, a possible early precursor of Alzheimer's disease, compared to cisgender people.²⁸ There may be a race- and/or ethnicity-based disparity related to subjective cognitive changes among transgender people.²⁹ Subjective cognitive changes were highest among transgender and nonbinary BIPOC people at 21.6% in one study, even compared to transgender White people.³⁰ However, there remains a pressing need for more dementia data disaggregated by gender identity.³¹

It is less understood whether, to what extent, or how dementia affects transgender people's experience of their gender identity. Studies have reported transgender people who created a backstory supporting their current gender identity, such as a transgender woman who told clinicians stories about birthing her children,³² or a transgender man who consistently

attempted to urinate standing up without a device or having had urethral lengthening.³³ Transgender people with dementia may forget that they have had gender-affirming surgeries or that they have been taking gender-affirming hormones, or may even not be aware that their gender expression has changed.³⁴ However, a newer qualitative sample showed that the transgender people interviewed had a deep sense of their gender identity and that none had forgotten it.³⁵

Ethnic and cultural dimensions including Indigeneity may create different understandings of how a core self functions with dementia. For example, Joan, a Métis Two Spirit person of Aboriginal and Canadian ancestry, understands her ethnicity as well as her gender to be mixed, and that her identities exist in liminal space. Therefore, her core self is accustomed to border crossing in a way that can accommodate cognitive changes.³⁶ In fact, scholars have called for reconsideration of the way gender is discussed in the context of dementia lest it be reduced to limited categories based on structurally biased conceptions of biology.³⁷ Structural considerations related to sex and gender have been noted not just in the US but globally.³⁸

C. Theorized Treatment Approaches for Transgender People with Dementia

Geriatricians and long-term care workers may be ill-equipped to establish and implement care pathways without a nuanced understanding of transgender identities. Best practices for person-centered care for patients with Alzheimer's disease call for clinicians to acknowledge³⁹ and then validate patients in the subjective reality they are experiencing at any given time.⁴⁰ Applying this protocol to a transgender patient living with dementia may seem to require acknowledging whichever gender identity they are expressing at that time as opposed to only validating their historical or past identity.⁴¹ Baril and Silverman call this a "trans-affirmative fluid approach," which may fit the situation but also may expose the patient to the risk of non-affirmation or even violence by clinicians who do not understand gender fluidity.⁴²

Avoiding acknowledgement of gender at all, whether by pronouns or by clothing or something else,⁴³ infantilizes the patient by removing their decision-making opportunities, as well as being dismissive of gender fluidity.⁴⁴

Affirming a binary gender could be an appropriate approach, if confirmed by the patient. Some transgender people may be profoundly unsettled by the prospect of their gender changing as their cognition changes, particularly if they understand their affirmed gender identity as a hard-fought achieve-

ment of gender congruence that they do not want to be threatened.⁴⁵ However, this "trans-affirmative stable approach" in isolation could imply that gender instability is a pathological symptom of dementia and that transgender people lack decisional capacity to be gender-fluid.⁴⁶ Nevertheless, this approach might be the one favored by many transgender people⁴⁷ — which raises the question, where does the voice of the transgender patient fit into the treatment plan?

D. The Perceived Powerlessness Feedback Loop

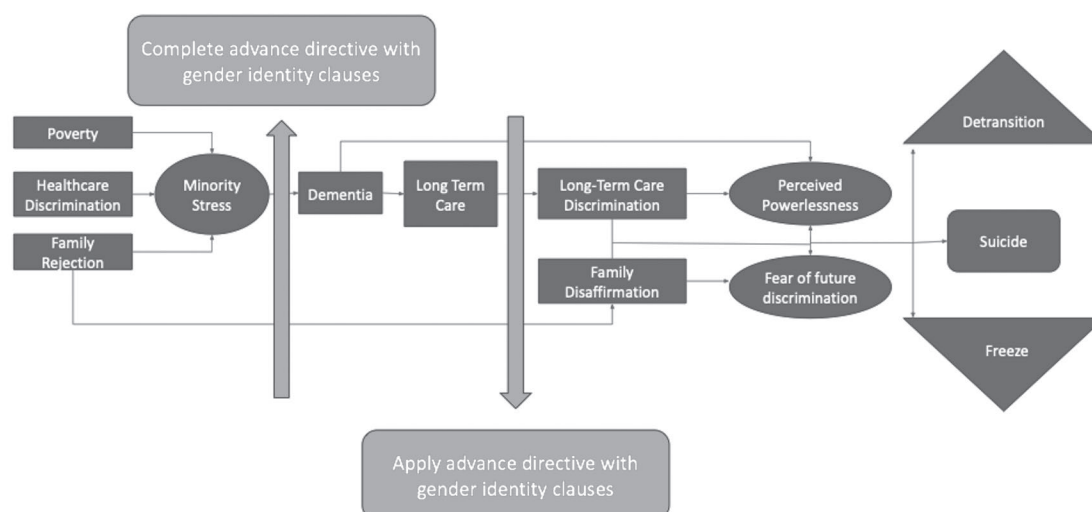
A feedback loop occurs when the output of a system is returned to the input, and transgender older adults can be caught in one. Transgender adults experiencing cognitive changes may be more likely to experience discrimination in healthcare settings in the future.⁴⁸ It seems that not only is chronic minority stress making transgender people sicker, but some healthcare providers who are supposed to be helping patients to mitigate the minority stress are making it worse by discriminating against patients: 64% of palliative care team members in one study reported that they believe that transgender patients are more likely to be discriminated against, and 21% reported actual observation of discrimination toward transgender patients.⁴⁹

Given that inverse relationship, transgender people understandably report fear of mistreatment and lack of affirmation of their gender identity in long-term care.⁵⁰ Transgender people may fear arbitrary termination of hormone therapy due to advanced age⁵¹ or after onset of cognitive changes⁵² (which has been reported by transgender people, even after ten years of hormone therapy⁵³). Transgender people may fear that their transness itself will be seen as a symptom of dementia⁵⁴ (also reported by transgender people, such as providers saying "you have memory issues, so I don't really know if I can trust what you're saying [about your gender]").⁵⁵

Transgender people thinking about end-of-life care report fear for their safety, particularly if they hold multiple marginalized identities: "The poorer you are, the blacker you are, being a transwoman — all make you more vulnerable."⁵⁶ Socioeconomic status and education may also affect transgender people's experience receiving healthcare.⁵⁷

Thus, the feedback loop continues: fear of accessing services has been shown to be a significant mediator across poor outcomes in both physical and mental health.⁵⁸ Experiences with healthcare discrimination in the past cause transgender people to fear additional discrimination and worse treatment in long-term care.⁵⁹ A transgender person's sense of their own agency to fight that discrimination may be compro-

Figure 1

Breaking the Feedback Loop

mised after the onset of cognitive changes. Indeed, if a transgender person is perceived by healthcare providers to be experiencing cognitive changes, their ability to advocate for themselves in long-term care settings may be discounted.⁶⁰ Loss of agency is the aspect of dementia that transgender people report the most fear about, because of perceived loss of control over their gender identity and expression.⁶¹

The powerlessness that transgender people perceive to result from the onset of cognitive changes has sown seeds of fear and anxiety about dementia deeply into many transgender people's sense of their future. There is clear evidence that older transgender people have specific concerns about dementia and end-of-life care.⁶² One in six transgender respondents to a 2022 survey reported concern about becoming disempowered if they need care because of cognitive changes, with transgender people of color reporting almost twice the level of concern as White transgender people.⁶³ These fears of not being affirmed or supported may make it hard to see a future of healthy aging.⁶⁴

This constellation of fears related to discrimination by long-term care providers and the perceived powerlessness to respond to it⁶⁵ may leave transgender people feeling frozen into this feedback loop, worrying that they will be treated as the wrong gender in long-term care, or that dementia will “steal their TNB identity” — one transgender woman worried “Am I just gonna forget who I am? Or that I’ve transitioned...[W]hat’s gonna happen to me there as I’m left alone?”⁶⁶ A transgender person’s expression of their gender to others may be one of the few acts of personal sovereignty that they perceive as available to them.⁶⁷

There might be exit ramps from the feedback loop if the patient has the resources to afford care at home⁶⁸ and/or gender-affirming medical procedures that might reduce the risk of involuntary disclosure of transgender status: “[I]t’d be difficult for me to pretend I wasn’t transgender. My body is not...boobs...and that stuff.”⁶⁹ However, higher rates of poverty may put these options out of reach. Some transgender people may feel the safest off-ramp is to express the gender assigned to them at birth⁷⁰ and “being relegated back into the closet.”⁷¹ For others the dysphoria associated with their birth sex forecloses this route and leads directly to hoping for fatal accidents or serious illness, or even thoughts of ending their life before needing institutional long-term care.⁷² **Figure 1**, “Breaking the Feedback Loop,” provides a graphic representation of a potential way forward.

E. Structural Interventions to Manage Fears of Transgender People

When the end of their life is the only off-ramp from aging, dementia, and long-term care discrimination that many transgender people see, there has been a broad systemic failure. Our society must respond to this emergency with creative solutions that use every tool at our disposal, including law and policy.

Advance directives are one form of medical decision-making and consist of documents that specify the healthcare treatment a person would want if they lost legal capacity to make decisions for themselves. States may vary slightly in the requirements or names of the documents in an advance directive, but they are generally easy to find.⁷³ An advance directive typically

includes a statement of treatment preferences (commonly called a living will) which usually becomes activated at end of life. Increasingly, advance directives include a statement of treatment preferences in the event of conditions which may reduce someone's legal decision-making capacity prior to end of life, such as dementia. Compassion and Choices maintains a Dementia Values and Planning Tool web form to help users create a dementia addendum to an advance directive.⁷⁴ Advance directives usually also contain a healthcare power of attorney in which a person designates a surrogate healthcare decision-maker to carry out their wishes if they are unable to do so themselves.

In the absence of express treatment wishes and/or

who begin expressing a different gender identity. In the absence of clear direction from clinical guidelines or the patient themselves, long-term care providers may be persuaded by non-affirming family members that the resident is not actually transgender.⁷⁹

To help avoid this outcome, a transgender person can designate a gender-affirming surrogate healthcare decision-maker. If a transgender patient can identify such a person in their life, they may be able to avoid a biased surrogate who may make harmful decisions.⁸⁰ Statements of treatment preferences that direct healthcare providers to provide gender-affirming care may also be useful in avoiding discrimination by non-affirming clinicians.⁸¹ A healthcare agent can also be

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directives to a healthcare agent, healthcare workers usually default to a patient's family members about the goals of patient care and treatment modalities to achieve those goals. Most states have a statute specifying default healthcare surrogate decision-makers that typically begin with spouse, then adult child, parent, and other family members related by marriage or blood. While some states have recently added close friends or nonfamily adults as surrogate decision-makers, they are at the bottom of the consultation hierarchy below family of origin.⁷⁵

Given the historical marginalization of transgender people, their family members may not be accepting or supportive of their relative's gender transition. In the absence of a written specification of a healthcare agent, an unsupportive family member may try to take over decisions about medical care,⁷⁶ and they may even seek to use this opportunity to undermine their relative's gender identity. For example, one transgender woman related: "The thing I fear the most is certain members of my family who might survive me ... and how they would put pressure on my own children to make sure I'm listed as my dead name and male."⁷⁷ For many transgender people, it is a realistic fear that their gender expression may be hampered or changed by unsupportive family of origin.⁷⁸

Long-term care providers may not be prepared for transgender people experiencing cognitive changes

assertive with advocacy in ways that may not feel safe for a transgender person to do themselves.⁸² A key competency for providers of healthcare to transgender people is advocacy to help patients with advance care planning to ensure that their wishes are respected.⁸³

Despite the peace of mind and additional certainty that can accompany setting down one's wishes ahead of time, uptake of advance directives in the US has been low. Only about one in three adults in the US has completed any type of advance directive.⁸⁴ Black and Latine people are almost four times less likely to have advance directives in place than White people,⁸⁵ though situating advance care planning in African American faith communities has been shown to be a promising practice.⁸⁶ LGBTQ people may avoid advance care planning out of fear of discrimination and doubt that their wishes would be honored by providers.⁸⁷

Transgender people are even less likely (as low as 13.1%)⁸⁸ than LGBQ people to have advance directives in place, especially in the southern US.⁸⁹ Some transgender people have said that the experience of gender transition made them feel they are "starting life anew" and that end-of-life planning seems too far off during this hopeful phase.⁹⁰ Other transgender people said that they "never imagined they could live long enough to grow old" and need an advance directive.⁹¹

Other reasons include basic practical considerations that prevent transgender people from pursu-

ing advance directives. For many transgender people, food, shelter, and basic life necessities take precedence over planning for what may seem like a distant future,⁹² particularly since these services are perceived to have high legal and administrative costs.⁹³ Additionally, many transgender people's support networks may be too thin to readily identify someone appropriate to serve as a healthcare proxy.⁹⁴

A study of gender non-conforming adults age 18–30 about gender-affirming end-of-life conversations found that only 2 out of 20 had talked with their family about their gender identity in the context of death.⁹⁵ In addition to the obstacles presented by the stigma of talking about death, plus the stigma of openly discussing gender identity, many of them also had struggled with mental health issues in the past that triply stigmatized such a discussion: these young adults were afraid that talking about death might lead their family to think they were contemplating suicide.⁹⁶ These obstacles were magnified for the many biracial participants in the study, who said negotiation of racial and ethnic identities during these conversations adds to their difficulty.⁹⁷

A recent study found that most Black, Latine, and multiracial respondents had a strong desire to complete an advance directive.⁹⁸ However, a study of Medicare claims data indicates that Black transgender beneficiaries receive the lowest rates of advance care planning services.⁹⁹

While these newer studies show the tide may be turning, there is generally a dearth of data about transgender people's use of advance directives that is disaggregated by race and ethnicity.¹⁰⁰ The Medicare study authors mentioned above note that while advance care planning interventions tailored for race and ethnicity have proven to be more successful in the general population, they were not aware of any advance care planning services tailored for transgender people of color, and they recommend the development of such interventions in collaboration with transgender patients of color.¹⁰¹ Such tailored services that take into account upstream discrimination and stigma have been described as an element of structural competency for both medical and legal professionals.¹⁰²

As mentioned above, Medicare has provided reimbursement since 2016 to providers for voluntary, face-to-face services provided by a physician or other qualified health professional to a patient, family member, caregiver, or surrogate about the patient's wishes for healthcare treatment if they become legally incapacitated.¹⁰³ These thirty-minute discussions can include discussion of advance directives and assisting the patient with completing appropriate forms.¹⁰⁴ Since

Medicare providers are already accustomed to reviewing advance directives, a document with specific gender-affirming instructions may help them provide the care that transgender people need.

However, the practice of advance care planning has not developed alongside the aging of the transgender population. Care staff need to be educated to be able to grapple with questions such as how to provide care to a transgender person who does not remember that they have transitioned, or whether to validate a past or present gender identity.¹⁰⁵ By asking about how transgender people understand their gender identity and what their values are when it comes to dementia, we can help to preserve autonomous decision-making for transgender people.

A detailed gender-affirming advance directive can provide guidance to clinicians about how a transgender person wishes their gender identity to be respected if they can no longer advocate for themselves. There are some objections based in ethics that advance care planning around gender identity may not account for future gender fluidity.¹⁰⁶ However, advance care planning can take into account that a transgender person understands their gender identity to be fluid (or even if not fluid today, they would welcome any gender fluidity that may develop as they age). Baril and Silverman advocate for a "Trans-Affirmative Fluid Crip- and Age-Positive" approach based in disability rights with two central tenets: cognitive changes that affect gender identity should not be seen as decline, and gender expression should be supported for transgender people living with dementia as much as it is for people without dementia.¹⁰⁷ In order to avoid ableism, priority must be placed on supporting the transgender person with retaining as much agency and decision-making capacity as possible.¹⁰⁸ Consideration must be given if gender-fluid patients are currently receiving gender-affirming medical treatments such as hormone therapy or daily dilation, which may not be able to be started and stopped simply, quickly or repeatedly.¹⁰⁹

G. Implementing Gender-Affirming Advance Directives

Practitioners should assist transgender people with advance care planning.¹¹⁰ It is important for our rapidly aging population that advance care planning is increased and brought to scale quickly. Advance care planning should be thought of as early life planning conversations that may help prevent acute situations where transgender patients need an advance directive but have not developed one.¹¹¹ In fact, in one study, several patients said they hope their clinician brings up advance care planning proactively, and by surfac-

Table 1

Guiding Questions and Advance Directive Clauses

Guiding Questions About Values		
I experience my gender identity as:		
A permanent transition from my past from the sex I was assigned at birth to the gender I am now.	A fluid state — sometimes I feel masculine. Other times I feel feminine. Sometimes I may feel neither. Sometimes I may feel both. Sometimes I feel some other combination of genders.	A less binary experience — I am masculine but am comfortable with some femininity, or I am feminine but am comfortable with some masculinity.
If I have forgotten that I am a transgender person and begin feeling like the sex I was assigned at birth, how would I want people around me to relate to me?		
I would want people to relate to my true self, the gender identity that I fought for a long time to be recognized.	I would want people to relate to me as whatever gender I present to them on any given day, regardless of my historical gender identity.	This question doesn't feel applicable to my situation.
The idea that I might one day have dementia and begin expressing a different gender identity:		
Is deeply unsettling to me. Expression of my gender identity is one of the most important ways that I exercise control over my life.	Seems like a normal part of life for me. I would not view gender fluidity as a decline in my ability to understand myself.	This question doesn't feel applicable to my situation.
One of the things I worry about with dementia is that someone from my family who does not support my gender identity will try to convince my care team that I'm "not really transgender."		
I worry about this and want to take actions to prevent this from happening.	This is not something I'm concerned about.	This question doesn't feel applicable to my situation.
I would feel less worried about dementia if I knew that people around me would have to follow my written directions about how to relate to me as a transgender person.		
Yes, I would want people to relate to me with my correct name and pronouns. I would want them to continue any medical treatments needed to preserve my gender identity.	Yes, my gender identity is fluid. I would feel violated if anyone forced me to dress a certain way or be called by different pronouns than how I felt on that day.	Although I feel sure about my gender identity today, I am not sure I would want to be forced to dress a certain way or be called by different pronouns if dementia caused me to see myself as a different gender.
These are my values with respect to gender identity and fluidity:		
My gender identity is something I fought hard to ensure that people around me recognize. I would not ever want to lose that.	Gender fluidity should be supported for people with dementia just as much as it is for people without dementia.	This question doesn't feel applicable to my situation.
When I think about dementia:		
It is important to me to keep the gender identity I have now, even if I might feel just as sure about a different gender identity after I have dementia.	My ability to direct my own life and gender expression in the moment is most important.	It feels wrong to try to guess today what my gender identity will be in the future.

Table 1 (Continued)

Guiding Questions and Advance Directive Clauses

How to Read the Next Section of the Table:		
If you answered mostly (a), you may want to write a gender-affirming advance directive. You may find more peace of mind when you think about dementia if you have written down the treatment you want to receive.	If you answered mostly (b), you may want to write a gender fluid advance directive. You might feel less fearful about dementia if you have written about your gender fluidity. It might help your care team if you say you would like to express your gender however it feels right.	If you answered mostly (c), you should still consider completing an advance directive, but specific gender identity clauses in an advance directive might not be the right answer. You might later regret having “boxed yourself in” to a particular gender identity that might not feel right anymore if you develop dementia.

Suggested Advance Directive Clauses to Add		
Gender-Affirming Treatment Preferences	Gender Fluid Treatment Preferences	No Special Treatment Preferences
During any period of treatment, I direct my physician, all medical personnel, and anyone who is caring for me to refer to me by the name of _____ and to use _____ pronouns in reference to me, my chart, and my treatment, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any gender-affirming treatment.	During any period of treatment, I direct my physician, all medical personnel, and anyone who is caring for me to refer to me by the name and pronouns that I am using for myself that day in reference to me, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any gender-affirming treatment.	No special treatment preferences
During any period of treatment, if I am unable to personally maintain my appearance, I direct my physician, all medical personnel, and anyone who is caring for me to do so to the extent reasonably possible, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related treatment.	During any period of treatment, if I am unable to personally maintain my appearance, I direct my physician, all medical personnel, and anyone who is caring for me to do so in accordance with my gender expression on that day, to the extent reasonably possible, irrespective of whether I have obtained a court-ordered name change, changed my gender marker on any identification document, or undergone any transition-related treatment.	No special treatment preferences
I want my healthcare representatives, agents, proxies, medical providers, family members, caregivers, long-term care providers, and other loved ones to know and honor my wishes regarding the type of care I want to receive if I develop an advanced stage of Alzheimer’s disease or another incurable progressive dementia. Regardless of my physical and mental state, I would like the following treatment: maintenance of my gender-affirming healthcare and gender expression.	I want my healthcare representatives, agents, proxies, medical providers, family members, caregivers, long-term care providers, and other loved ones to know and honor my wishes regarding the type of care I want to receive if I develop an advanced stage of Alzheimer’s disease or another incurable progressive dementia. I value my gender fluidity, do not see it as a symptom of cognitive decline, and want to be supported in the gender expression that I am showing on that day or occasion, which may change in the future.	No special treatment preferences

Table 1 (Continued)

Guiding Questions and Advance Directive Clauses

Suggested Advance Directive Clauses to Add		
Gender-Affirming Healthcare Powers of Attorney	Gender Fluid Healthcare Powers of Attorney	No Special Healthcare Powers of Attorney
<p>My Healthcare Agent's authority to act on my behalf concerning my medical care includes but is not limited to, requesting, asserting my rights to, giving consent for, and withdrawing consent for any medical treatment related to maintaining my gender identity, including but not limited to:</p> <ol style="list-style-type: none"> 1. Administration of exogenous hormones, including but not limited to estrogen, androgen blockers, and testosterone, as applicable; 2. Ongoing treatment related to surgical interventions, including but not limited to continued dilation of vagina, scar treatment such as silicone, collagen, massage, and any other medically necessary treatment, as applicable; 3. Any other diagnostic and treatment procedures ordered by or under the authorization of a licensed healthcare provider under Medical Orders for Scope of Treatment. 	<p>My Healthcare Agent's authority to act on my behalf concerning my medical care includes but is not limited to, requesting, asserting my rights to, giving consent for, and withdrawing consent for:</p> <ol style="list-style-type: none"> 1. Use of the name, pronouns, and forms of address that I am using that day. 2. Clothing and grooming in accordance with my gender expression on that day. 	No special healthcare powers of attorney
Use of my affirmed name, pronouns, and forms of address, to preserve my dignity as a transgender person, in all healthcare contexts.		No special healthcare powers of attorney
Placement, housing, clothing, grooming, medical records including death certificate, obituary, and disposition of my remains are all done in accordance with my gender identity, affirmed name, pronouns, and forms of address, including after my death. This authority takes precedence over any provision to the contrary in any prepaid funeral contract.		No special healthcare powers of attorney
These powers are enforceable regardless of whether I have obtained a court-ordered name change, changed the gender marker on any identification document, or undergone any transition-related medical treatment.		No special healthcare powers of attorney

ing the issue earlier in life, transgender patients will have more time to locate an appropriate person to serve as healthcare proxy.¹¹²

Given that advance care planning for dementia is a multidisciplinary process that may involve both physical and mental healthcare providers as well as legal staff and community advocates, the multidisciplinary approach of medical-legal partnerships (MLPs) may

make them a good laboratory to begin asking these questions. LGBTQ primary care MLPs can provide expertise on potentially health-harming legal needs that arise for LGBTQ patients.¹¹³ It is also important to not overlook faith channels such as chaplains and spiritual care givers in hospice care.¹¹⁴ At the same time, advance care planning should not be reserved for end-of-life discussions. Advance care planning can

best be thought of as ongoing health planning that can be revisited and revised periodically as circumstances change, including regular check-ins to obtain ongoing consent or assent to the terms of advance directives.¹¹⁵

Practices should adapt existing dementia planning tools to include guiding questions about how a transgender person views gender fluidity and whether and how they might want to memorialize those thoughts in an advance directive. This author in consultation with SAGE and Transgender Law Center has developed a tool, summarized in **Table 1**, that presents guiding questions for transgender people to use to help them identify their values around gender identity and dementia, depending on whether a person's gender identity feels more set or more fluid, and clauses that can be included in advance directives.¹¹⁶

Limitations

The guiding questions tool mentioned above has not yet been validated by research with transgender people, particularly whether these approaches would be effective interventions for BIPOC transgender people. The disproportionality of subjective cognitive changes among BIPOC transgender people should make these communities the top priority for further research, including effective outreach methods.

There are also ethical questions that need to be explored further in order to further refine the tool. For example, if a transgender person feels strongly that they want their gender identity to be recognized throughout processes of cognitive change, it is unclear how, or even whether, clinicians will be able to honor the patient's wishes if those wishes would prove to be upsetting to the patient when dementia advances.

Though the research base about the physical, mental, and emotional processes of aging among transgender adults is developing, there are significant gaps that could affect the viability of the planning tool. Without greater understanding or protocols about how long transgender people can or should include gender-affirming hormones and/or post-surgical interventions in their routine care, it is hard to know the extent to which those considerations may affect the manner in which new or increased gender fluidity can be affirmed in a patient undergoing cognitive changes.

Conclusion

Transgender people need more research in almost every area of health, but especially in the adaptation of successful interventions to be culturally responsive to transgender people with multiple marginalized identities. While this approach may be the road (thus far) not taken, it may be a more health-sustaining off-

ramp from fear and anxiety for transgender people encountering dementia than the limited options that currently exist.

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